

# **EXHIBIT 9**

**IN THE UNITED STATES DISTRICT COURT  
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI  
JACKSON DIVISION**

STATE OF MISSISSIPPI;  
STATE OF ALABAMA;  
STATE OF ARKANSAS; COMMONWEALTH OF  
KENTUCKY; STATE OF  
LOUISIANA; STATE OF MISSOURI;  
and STATE OF MONTANA,

*Plaintiffs,*

v.

XAVIER BECERRA, in his official  
capacity as Secretary of Health and  
Human Services; THE UNITED  
STATES DEPARTMENT OF  
HEALTH AND HUMAN SERVICES;  
CHIQUITA BROOKS-LASURE, in her  
official capacity as Administrator of the  
Centers for Medicare and Medicaid  
Services; THE CENTERS FOR  
MEDICARE AND MEDICAID  
SERVICES; THE UNITED STATES  
OF AMERICA,

*Defendants.*

No. 1:22-cv-113-HSO-RPM

**DECLARATION OF KARI THATCHER**

I, Kari Thatcher, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. As Co-Chair of the Greensboro Health Disparities Collaborative (the “Collaborative”), I am authorized to provide this declaration on behalf of the Collaborative, a proposed intervenor in this case. I have been the Co-Chair of the Collaborative since 2017 and a member of the Collaborative since 2015.

3. I also serve as the Board Chair of The Partnership Project, Inc.—an organization which helped create and is affiliated with the Collaborative. The Partnership Project began in 1993 to promote community building through training and the formation of relationships between fragile communities and outside resources. It formed the Collaborative in 2003 to address issues of racial and ethnic disparities in health care in Greensboro, North Carolina and across the United States. In the same year, The Partnership Project reorganized as a 501(c)(3) non-profit to better support the work of the Collaborative.
4. I received my master's degree in Public Health from the University of North Carolina in 2015. I received a bachelor's degree from Chapman University in 2001.
5. I am currently a free-lance consultant on issues relating to health equity and public health. I spend most of my time working with the Collaborative and the Partnership Project. I occasionally receive stipends for the work I do with the Collaborative. The Partnership Project pays me on a Form 1099 for organizing a racial equity presentation known as A Groundwater Approach to Understanding Racial Inequity.

#### **Background on the Collaborative**

6. The Collaborative has approximately 50 members, which include health care providers, health care and public health scholars, representatives of community organizations, and other representatives from the Greensboro community. Our membership also includes people who are eligible for Medicare and receive health coverage through Medicare, as well as physicians who provide medical services to Medicare recipients. Absent a financial-hardship exception, each member of the Collaborative pays \$35 annually in dues.
7. The Collaborative has six officers: two co-chairs, a vice chair, a secretary, an assistant secretary, and a treasurer. All of the Collaborative's officer positions are volunteer

positions. As the Co-Chair of the Collaborative, my duties include providing strategic direction for the organization, cultivating strong relationships with partner organizations, and fostering leadership and project-management skills among the Collaborative's members.

8. The Collaborative also has several volunteer committee chairs. Our standing committees center around outreach, social media, membership, and publications and dissemination. Periodically, the Collaborative convenes ad hoc committees for special projects.
9. The Collaborative grew out of the Partnership Project's recognition that unequal treatment based on race and ethnicity exists in the healthcare system across the United States and that inequality in healthcare literally has life-and-death consequences. As just one example, a 2003 report by the Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care and commissioned by Congress documented substantial evidence that (1) the quality of health care in America varies across racial and ethnic groups, even when controlling for other factors such as insurance status and income, and (2) disparities in treatment, including provider attitudes, and policy choices contribute to health inequalities. Specifically, the report found that people of color received lower quality healthcare than white people and that these racial disparities in health care are associated with higher death rates for Black Americans across a range of health conditions.<sup>1</sup> The study showed that Black women died of breast cancer at much higher rates than white women, even though white women were diagnosed with breast cancer at much higher rates

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<sup>1</sup> Brian D. Smedley, Adrienne Y. Stith, & Alan R. Nelson, eds., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Inst. of Medicine on Understanding & Eliminating Racial & Ethnic Disparities in Health Care 1-2 (2003), <https://pubmed.ncbi.nlm.nih.gov/25032386/>.

than Black women at the time.<sup>2</sup> The study also found that the discriminatory treatment of Black women is a contributing factor in these disparate outcomes.

### **The Collaborative's Involvement in Health Equity Research**

10. The Collaborative and its members conduct and support research on racial and ethnic health care disparities.<sup>3</sup> The Collaborative has a particular interest in researching disparities in cancer treatment and in outcomes from that treatment because Black patients have the highest death rates and shortest survival of any racial group in the United States for most types of cancer.<sup>4</sup> The American Cancer Society has reported that Black women are 40 percent more likely to die of breast cancer than white women.<sup>5</sup> Most people living with cancer are older adults; many are Medicare recipients.

11. In 2006, the Collaborative obtained a two-year grant from the National Institutes of Health (NIH) for a Cancer Care and Racial Equity Study (CCARES) to investigate the complexities of institutional racism and how it relates to disparities experienced by Black and white breast cancer survivors within a local community. The Collaborative worked with the Cone Health Cancer Center on this study. Cone Health is a private, not-for-profit healthcare delivery system based in Greensboro that operates hospitals and various care

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<sup>2</sup> *Id.* 54-55.

<sup>3</sup> *E.g.*, Chandra Ford, et al., *Racism: Science & Tools for the Public Health Professional*, Am. Pub. Health Ass'n (2019); 01/01/2019; Kristin Z. Black, et al., *'It's Like You Don't Have a Roadmap Really': Using an Antiracism Framework to Analyze Patients' Encounters In the Cancer System*, Ethn Health (2018) (attached as Exhibit A); Katrina R. Ellis, et al., *Racial Differences in the Influence of Healthcare System Factors on Informal Support for Cancer Care Among Black and White Breast and Lung Cancer Survivors*, Fam Cmty. Health (2020).

<sup>4</sup> *See* Am. Cancer Soc'y, *Cancer Facts and Figures for African Americans 2019-2021* 1 (2021), <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-african-americans/cancer-facts-and-figures-for-african-americans-2019-2021.pdf>.

<sup>5</sup> *Id.* at 14.

centers. It employs more than 10,000 physicians and other medical providers caring for tens of thousands of residents of North Carolina, many of whom are Medicare recipients.

12. CCARES collected qualitative data from Black and white breast cancer survivors within the Greensboro community about challenges that those patients experienced during their cancer treatment. CCARES collected this data using the Critical Incident Technique—a system of semi-structured interviews that are designed to aid recall of past critical events or incidents.

13. The study revealed that Black survivors of breast cancer were not adequately supported by the existing peer-support organizations.<sup>6</sup>

14. After CCARES revealed disparate cancer care treatment experiences, the Collaborative sought to obtain a more robust understanding of the “pressure points” in the cancer care journey where these patterns of racial disparities in treatments arose, and real-time data to make it possible to intervene as they were happening, therefore the Collaborative began developing interventions with these goals in mind.<sup>7</sup> We applied for and received in 2012 a second five-year grant from NIH’s National Cancer Institute to conduct the Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) study. The ACCURE study was a collaborative effort with the University of North Carolina at Chapel Hill, The Partnership Project, Inc., Cone Health, and the University of Pittsburgh Medical Center. The Collaborative developed and implemented the study, which collected information on 89,454 Black and white patients with stage 1 or stage 2 breast cancer or lung cancer. The study involved breast cancer and lung cancer patients because breast cancer kills more

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<sup>6</sup> Yonas, Michael et al., *Cancer Care and Racial Equity Study (CCARES): An Innovative Community and Academic Model for Investigating Disparities in Systems of Breast Cancer Care* (2008).

<sup>7</sup> Ex. A at 5-8.

Black women than any other cancer and lung cancer kills more Black men than any other cancer. Many of the patients in the study were Medicare recipients. The goal of the study was to test whether a multipronged intervention that changed the systems of care could improve the experiences of Black patients undergoing treatment.

15. The ACCURE study incorporated four major interventions at Cone Health and Hillman Cancer Center. *First*, each cancer center’s “nurse navigator” received a two-day racial equity training (the same one that is required to join the Collaborative). Nurse navigators also received training from Dr. Sam Cykert—a member of the Collaborative—on how to identify and address challenges that limit care for Black cancer patients, such as medical mistrust, low self-efficacy, and communication barriers. In addition to these trainings, the nurse navigator received ongoing education about implicit bias, unintentional attitudes, and institutional racism and how these concepts manifest in policies, practices, and cultural norms. *Second*, the study developed an electronic alert system based on patient electronic health records for each cancer center to use. The system alerted the nurse navigator when a patient participating in the study missed an appointment or did not reach an expected milestone in care (i.e., scheduling diagnostic testing, undergoing surgery, beginning chemotherapy). Around 300 patients who were diagnosed with cancer from April 1, 2013 to March 31, 2015 agreed to include their information in the electronic system and work with a nurse navigator. *Third*, each cancer center selected a “physician champion.” The physician champion received anti-racism training, garnered buy-in from other physicians for the philosophy of anti-racism in medicine, and served as a liaison between the nurse navigator and other physicians during the study. *Fourth*, the staff of each cancer center were offered continuing education sessions on implicit bias, unintentional attitudes, and

institutional racism, known as Health Equity and Education Training (HEET) sessions. Periodically, these continuing education sessions also included reporting the hospitals' own data on patient outcomes disaggregated by race back to them for review.

16. The ACCURE study findings (attached as Exhibit B) showed that a racial equity plan had a substantial impact on successful treatment. For example, before the program, 79.8% of Black patients and 87.3% percent of white patients completed treatment. But for those who received the benefit of ACCURE's interventions, the treatment completion rates increased for both racial groups: 88.4% of Black patients and 89.5% of white patients completed treatment. In short, race-related differences were resolved while both Black and white patients had improved outcomes. And after considering patients' income, health insurance and diagnosis of other illnesses, the Black-white difference was reduced by 8%. Reducing disparities in treatment completion rates is critical, because studies show that differences in treatment completion play a major role in explaining racially disparate mortality rates for lung cancer and breast cancer.<sup>8</sup> The ACCURE study projected that the study's interventions could yield similar benefits for other common chronic illnesses, including other types of cancer.<sup>9</sup>

17. The ACCURE study involved anti-racism training called Health Care Equity and Training (HEET) that focused on issues of racial and ethnic health disparities. That training was provided to Cone Health and University of Pittsburgh Medical Center staff members, including the nurse navigators and oncology physicians. HEET was developed with the participation of the Collaborative's members. Members of the GHDC also served as HEET trainers.

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<sup>8</sup> Ex. B at 14 (collecting studies).

<sup>9</sup> *Id.* at 15.



18. The results of the ACCURE study have sharpened the Collaborative's focus on recruiting more hospitals to develop and implement anti-racism interventions, and on providing consulting services for those hospitals. ACURE4Moms is one example of those efforts. ACURE4Moms is a randomized controlled trial that aims to improve maternal health outcomes, satisfaction, and communication, particularly for Black moms. The Principal Investigator of ACURE4Moms is a member of the Collaborative and a researcher at the University of North Carolina Chapel Hill. Additional members of the Collaborative support ACURE4Moms in various capacities. For example, I plan to work as an Observer for the ACURE4Moms' MHEET (Maternal Health Equity Education Trainings) and collect process evaluation data.
19. The Collaborative is striving to increase its membership base and financial resources in order to extend its reach geographically and to wider range of health conditions.

#### **The Collaborative's Involvement in Health Equity Programming**

20. In addition to CCARES and the ACCURE study, the Collaborative assists in grassroots programming to advance health equity, including racial equity workshops. Members of the Collaborative often serve as trainers in anti-racism trainings facilitated by a national organization called the Racial Equity Institute, and routinely hosted by The Partnership Project. Participation in one of these anti-racism trainings is a pre-requisite for joining the Collaborative. The Collaborative cannot fulfill its mission unless health care providers understand racial inequity and how to eliminate it. For this reason, the Collaborative believes that anti-racism training is important for *all* health care providers—even those who are not consciously racist.

21. “Phase 1 Racial Training” is a two-day, 16-hour seminar where a team of facilitators leads a small group (approximately 30 people) through a series of exercises are designed to develop the capacity of participants to better understand racism in its institutional and structural forms. Moving away from a focus on personal bigotry and bias, this workshop presents a historical, cultural, and structural analysis of racism.
22. The Partnership Project hosted ten Phase 1 trainings in 2022, typically attended by about 35-40 people. A wide range of people with varying backgrounds attend the training, including teachers, physicians, nurses and others in medicine, administrators of non-profits organizations, and members of community groups. The registration fees for these trainings supply The Partnership Project’s primary source of annual revenue. The Partnership Project sets regular, group, and student rates for these trainings, however we adhere to a “pay what you can” model and maintain a scholarship fund in memory of one of our founders, Mrs. Nettie Coad, to support access for anyone wishing to attend; the organization never turns anyone away due to an inability to pay. Phase 1 training is a prerequisite to membership in the Collaborative.
23. At least one of the Collaborative’s members is a physician in Greensboro and shared with me that his medical practice has meaningfully improved as a result of attending the Phase 1 and Phase 2 anti-racism trainings. The Greensboro physician shared that he was once skeptical of and offended by the notion that medical professionals provide disparate care based on implicit racial biases, and that most physicians that he works with share this mentality. His viewpoint began to change when an investigator came to Cone Health to begin laying the framework for the ACCURE study. The results of the ACCURE study led the Greensboro physician to become a member of the Collaborative and cemented his

assessment that affirmative anti-racism efforts are necessary to reduce racial disparities in health care and improve treatment outcomes for all patients. He told me that he realized that the existence structural racism makes systemwide anti-racism efforts especially important. Structural changes, as opposed to simply correcting individual biases, are required to overcome racism in the healthcare system as a whole precisely because disparate treatment is present even when bigotry is not. He shared with me that he believes that all medical providers would benefit from anti-racism training, but that many providers are unlikely to overcome their inherent skepticism of anti-racism programming without appropriate incentives like the Merit-Based Improvement Payment System.

24. Another member of the Collaborative, Dr. Sidney Callahan, provides medical care to individuals who are eligible for and receive Medicare. Dr. Callahan shared with me that efforts by the Department of Health and Human Services (HHS) to improve Medicare services for people of color, such as the MIPS anti-racism plan improvement activity, are especially important for older patients as that segment of the population is more likely to have experienced overt and government-sanctioned discriminatory policies including segregated housing, education and healthcare that have led to disparities in health outcomes.

#### **The Collaborative's Interest in Anti-Racism Incentives for Health Care Providers**

25. The availability of the MIPS anti-racism plan improvement activity will significantly advance the Collaborative's mission to resolve issues related to health disparities. The improvement activity gives to health care providers an incentive to assess racial and ethnic gaps in their provision of healthcare and identify ways they can intervene and resolve such

disparities. The benefits of these evaluations and interventions have been the core subject of the Collaborative's research and the aim of its trainings.

26. By contrast, the elimination of the MIPS anti-racism plan improvement activity would have a detrimental impact on our programs and ability to accomplish our mission to empower and establish structures to resolve racism. Financial incentives are necessary to overcome the time, financial, and psychological barriers to creating and implementing anti-racism plans in the medical profession. Without the anti-racism plan improvement activity, fewer health care providers are likely to work with us and develop programs to advance our mission.
27. Absent financial incentives from the MIPS anti-racism improvement activity, the Collaborative will have to divert financial resources from research and other programming and put those resources toward increasing clinician buy-in for anti-racism planning.
28. Plaintiffs' suit, if successful, will also inevitably divert resources from the Collaborative's mission. In recent years, the Collaborative's primary source of funding has been the fees that the Collaborative charges to hospitals and other organizations for health equity consulting and health equity presentations. Plaintiffs' challenge to the MIPS anti-racism improvement activity rests on the premise that the anti-racism philosophy that the Collaborative endorses and teaches to others, including medical providers, is "bad medicine" and "encourages doctors to elevate faddish theories about race above patient care." If the Court strikes down the MIPS anti-racism improvement activity on this basis, then health care providers, philanthropists, and health insurance companies will likely be deterred from seeking out and paying for the type of health equity education that the Collaborative provides. Without this funding, the Collaborative will have to increase its

membership dues, increase the cost of its anti-racism trainings, or substantially divert its focus on research and education to fundraising.

29. The Collaborative has interests in defending the MIPS anti-racism improvement activity that diverge from HHS, the Centers for Medicare and Medicaid Services, and the individual defendants (“Agency Defendants”) in this case. The Agency Defendants have a general interest in maintaining the breadth of the Department’s rulemaking authority and defending the scope of the immunity conferred by 42 U.S.C. § 1395w-4(q)(13)(B). By contrast, the Collaborative has a specific interest in refuting the premise of Plaintiffs’ theory: that encouraging Medicare Part B providers to create and implement an anti-racism plan is detrimental to the health of white patients. Left unrefuted, Plaintiffs’ theory will undermine the research that the Collaborative conducts and supports, will increase antagonism toward anti-racism in health care, and will dissuade health care providers from participating in the anti-racism trainings that the Collaborative’s members help facilitate – and importantly, will result in preventable human suffering and death.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Kari Thatcher

Declarant’s Signature

5/11/2023

Date

Kari Thatcher

Declarant’s Printed Name

# **EXHIBIT A**



# HHS Public Access

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## ***'It's like you don't have a roadmap really': Using an antiracism framework to analyze patients' encounters in the cancer system***

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## **Abstract**

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**Disclosure Statement:** The authors have no conflicts of interest to disclose.

**Background:** Cancer patients can experience healthcare system-related challenges during the course of their treatment. Yet, little is known about how these challenges might affect the quality and completion of cancer treatment for all patients, and particularly for patients of color. Accountability for Cancer Care through Undoing Racism and Equity is a multi-component, community-based participatory research intervention to reduce Black-White cancer care disparities. This formative work aimed to understand patients' cancer center experiences, explore racial differences in experiences, and inform systems-level interventions.

**Methods:** Twenty-seven breast and lung cancer patients at two cancer centers participated in focus groups, grouped by race and cancer type. Participants were asked about what they found empowering and disempowering regarding their cancer care experiences. The community-guided analysis used a racial equity approach to identify racial differences in care experiences.

**Results:** For Black *and* White patients, fear, uncertainty, and incomplete knowledge were disempowering; trust in providers and a sense of control were empowering. Although participants denied differential treatment due to race, analysis revealed implicit Black-White differences in care.

**Conclusions:** Most of the challenges participants faced were related to lack of transparency, such that improvements in communication, particularly two-way communication could greatly improve patients' interaction with the system. Pathways for accountability can also be built into a system that allows patients to find solutions for their problems with the system itself. Participants' insights suggest the need for patient-centered, systems-level interventions to improve care experiences and reduce disparities.

### Keywords

cancer health disparities; systems-level interventions; community-based participatory research; racial equity

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It is well documented that cancer patients can experience healthcare system-related challenges during the course of their treatment (Institute of Medicine 1999, 2008). Poor patient-physician communication and lack of emotional and instrumental support have been commonly reported by breast cancer patients (Carroll et al. 2010; Kranick et al. 2010; Roberts et al. 1994). Lung cancer patients have reported high levels of unmet physical, psychological, and informational supportive care needs (Li and Girgis 2006; Sanders et al. 2010). In addition, navigating cancer care across multiple providers and clinical settings have been noted as burdensome for cancer patients (Freeman and Rodriguez 2011).

Systems-level challenges warrant greater attention given racial/ethnic disparities in cancer care. Compared with White cancer patients, Black cancer patients are less likely to be diagnosed at early stages (Bradley, Given, and Roberts 2001; Howlader et al. 2013; DeSantis, Naishadham, and Jemal 2013), undergo guideline-concordant treatments (Samuel et al. 2014; Lathan, Neville, and Earle 2008; Keating et al. 2009), report trust and shared decision-making with providers (Siminoff, Graham, and Gordon 2006; Gordon et al. 2006), and receive palliative and supportive care (Cleeland et al. 1994; Payne, Medina, and Hampton 2003; Smith, Earle, and McCarthy 2009). Despite decades of documenting racial disparities in cancer survival, Black breast cancer patients continue to initiate treatment later



(Gorin et al. 2006) and be treated less completely than their White counterparts (Voti et al. 2006; Hershman et al. 2005; Bickell et al. 2006; Berry et al. 2009). Moreover, Black lung cancer patients are more likely than Whites to make a decision, either independently or mutually with their physicians, to not pursue surgical resection, which is the only reliable curative treatment (McCann et al. 2005; Farjah et al. 2009; Cykert et al. 2010). Reasons for racial variations in quality and completion of cancer care are not well conceptualized or documented, and they vary by type of condition, socio-demographic variables, economic factors, and various cultural preferences, attitudes, and reservoirs of knowledge about disease etiology, prevention, and treatment (Rimer 2000; Van Ryn and Burke 2000; Tejeda et al. 2017; Haozous and Knobf 2013). Despite the clear need, interventions that address systems-level challenges to enhance equity, quality, and completion of cancer treatment are missing from cancer prevention and control research. This paper shares findings from formative work aimed to understand patients' cancer center experiences, explore racial differences in experiences, and inform systems-level interventions.

## Background

### Background on ACCURE Partnership and Intervention

To address this gap, our community-academic-medical partnership implemented and evaluated Accountability for Cancer Care through Undoing Racism and Equity (ACCURE), a systems-change intervention aimed at reducing race-specific gaps in treatment initiation and completion among early stage Black and White breast and lung cancer patients. Funded by the National Cancer Institute (NCI), ACCURE utilized a community-based participatory research approach (CBPR) (Schaal et al. 2016; Oh et al. 2016; Israel et al. 1998) with guidance and governance provided by the Greensboro Health Disparities Collaborative (GHDC), a 15-year old CBPR partnership of community, academic, and medical organizations. GHDC's mission is 'to establish structures and processes that respond to, and build the capacity of, communities and institutions in defining and resolving issues related to racial and ethnic disparities in health' (Schaal et al. 2016; Yonas et al. 2006; Yonas, Aronson, Coad, et al. 2013; Yonas, Aronson, Schaal, et al. 2013). GHDC is committed to using an antiracism approach informed by the Undoing Racism (UR)<sup>®</sup> framework (The People's Institute for Survival and Beyond 2015). All members of GHDC have completed a two-day antiracism training based on that model. The foundation of this training is to provide participants with a common understanding of antiracism language and to establish a lens for analyzing the structure of power in US institutions and systems. ACCURE, GHDC's second NCI-funded study, built on findings from prior research, the Cancer Care and Racial Equity Study (CCARES), which, using critical incident analysis, an innovative interviewing technique, with Black and White cancer survivors, identified systems-level gaps, such as lack of race-specific data related to treatment completion (Yonas, Aronson, Schaal, et al. 2013).

ACCURE was developed by the GHDC as an intervention to respond to the systems-level gaps identified in the literature and our CCARES research findings. ACCURE included four innovations with the goal of reducing gaps in treatment initiation and completion between Black and White cancer patients and tested the intervention in two cancer centers, one a

regional cancer center in the south and the second a large academic cancer center in the northeast. Innovations included, first, a nurse navigator, specially trained in utilizing a racial equity lens to work with Black and White breast and lung cancer patients to identify and address practical, emotional, and communication issues. The goal was for the navigator to serve as a two-way conduit between the patient and the cancer care system to address issues during the full continuum of care. Second, a real-time patient registry was developed to alert the navigator when patients did not reach timely treatment milestones (e.g., attending appointments, completing radiation treatments), allowing the navigator to address issues early enough to prevent compromises of quality and completion of care. The registry also aggregated provider-level and practice-level data, allowing clinicians to examine race-stratified care quality metrics (e.g., time between diagnosis and first treatment, percentage of early stage lung cancer patients referred for lobectomy) of their own patient panels as compared to practice averages and to published literature. Third, the nurse navigator collaborated with specific Physician Champions at each site for each cancer type to bring these race-specific clinical performance reports to the attention of practitioners to ensure equity in quality and completion of care. Finally, ACCURE offered quarterly Healthcare Equity Education and Training (HEET) sessions for medical and administrative staff members at each site. These interactive sessions were designed to introduce the staff to: systems-level issues of transparency and accountability, a racial equity lens, and concepts of unconscious bias and its effect on patient care.

### **Principles of Undoing Racism® Informing ACCURE**

The concepts of antiracism are at the core of ACCURE and its focus on systems-level change to reduce gaps in cancer care and outcomes between Black and White patients. Antiracism training has grounded our partnership in the history of racism in the US and the laws, policies, and procedures which have perpetuated a system of power that advantages some (White people) and disadvantages others (primarily people of color). The legacy of this structural racism is evident in all of the systems that affect people's lives and opportunities (e.g., education, criminal justice, healthcare) and the disparate outcomes (e.g., achievement gap, mass incarceration, health disparities) that disproportionately burden people of color (Hayes-Greene and Love 2016). The antiracism framework promotes understanding and a common language, and also provides a racial equity lens and tool (the analysis of power and authority) to gain understanding of how power shapes our institutions/systems as a first step towards generating systems-level strategies to intervene.

In particular, ACCURE draws on the antiracism principles of transparency (technocratic protocols and narrow knowledge) and accountability (technical language and fragmented power) which affect how systems operate, and the roles of gatekeepers who can impede or advance access, resources, policies, and procedures which affect how individuals experience and are treated in institutions or systems. ACCURE's intervention components were designed with an antiracism lens to address specific exposures and circumstances that make cancer care vulnerable to institutional racism (James et al. 1984; Geronimus 2000), interrupt the pathways through which these occur (McEwen 1998; Wadhwa et al. 2001; Lu and Chen 2004), with the explicit goal of changing structures that obstruct transparency and accountability. The absence of transparency and accountability in a system can lead to

unequal access to information and resources, therefore exacerbating racial inequities (The People's Institute for Survival and Beyond 2015).

### **Practices of Undoing Racism® Informing ACCURE Focus Group Analysis**

In the research described here, we drew on a critical practice within the UR® framework, an analysis of power and authority. The goal of this analysis is to examine the relationships between communities and institutions, and facilitate a critical analysis of structural racism by addressing issues of transparency and accountability, which affect equitable treatment. According to the People's Institute for Survival and Beyond (PISAB), which initiated these principles and practices, 'the world is controlled by powerful systems with historically traceable roots. Once people are shown how they benefit from or are oppressed by those systems, they can work together to change the system' (Shapiro 2002, 100). PISAB's analysis of power and authority process also brings to light the role of gatekeepers within systems who can grant access to resources and who have power over the individuals who enroll in the system.

To inform intervention development, particularly the Healthcare Equity and Education Training sessions for providers and staff at our partner cancer centers, ACCURE conducted a formative study engaging Black and White cancer survivors in an examination of the cancer care experience. The goal of this investigation, carried out through focus group discussions, was to explore patients' perspectives on treatment and identify places in the cancer care system where patients encountered critical incidents, also referred to as pressure points (Yonas, Aronson, Schaal, et al. 2013), that influenced the quality and completion of their cancer treatment.

Once the focus group data were collected, we sought to apply the principles and practices of antiracism by using the analysis of power and authority as a tool and a lens to analyze the transcripts and identify pressure points, or encounters within the care and treatment experience of Black and White breast and lung cancer patients at two different cancer centers, that affected their ability to navigate the cancer care system and complete their care plan. In doing so, we focused on the UR® principles lack of transparency (e.g., obtuse vocabulary/jargon, inconsistent information, impersonal communication modes, inflexible protocols, unclear procedures) and lack of accountability (e.g., unclear procedures for collecting and monitoring information on standards of care and for decision-making, not knowing about deviations from standards of care) from the cancer care system to the patients.

Few studies have applied CBPR principles (Israel et al. 1998) to examine patient perspectives on their cancer care experiences. Moreover, no studies to our knowledge have examined these experiences through an antiracism lens. This paper reports on the findings from the focus groups we conducted with cancer patients and analyzed with an antiracism lens. In this paper we: (1) describe our approach to applying the Undoing Racism® framework's analysis of power and authority (Schaal et al. 2016) as a tool to understand the experiences of Black and White stage 1-2 breast and lung cancer patients at two cancer centers; (2) discuss our findings on pressure points during care that influenced the quality and completion of their cancer treatment; and (3) highlight race-specific differences that are

critical to attend to if we are to improve transparency and accountability for equity in cancer care experiences.

## Methods

### Participant Selection and Data Collection

To elicit experiences of cancer patients during their journey through the cancer care system, we conducted eight focus groups with non-Hispanic Black and White breast and lung cancer survivors. Patients were recruited through their oncologists at the Cone Health Cancer Center (CHCC) and UPMC Hillman Cancer Center (UPMC CC). The CHCC is part of a regional hospital system and UPMC CC is a university teaching hospital. The requirements for participation were: (1) diagnosed with stage 1-2 breast (women only) or lung cancer (women and men); (2) received cancer care at CHCC or UPMC CC; and (3) completed treatment in the previous 12 months. Four race and cancer type specific focus group sessions were conducted (i.e., Black patients with breast cancer, White patients with breast cancer, Black patients with lung cancer, and White patients with lung cancer) at each cancer center for a total of eight focus groups.

The goal of the focus groups was to probe patients' experiences for pressure point encounters in which they felt encouraged (or discouraged) to continue their treatment and empowered (or disempowered) by the treatment process in order to understand systems-level protocols, procedures, and encounters that affect patients' treatment experiences, decisions, and completion rate and, ultimately, differential outcomes (Table 1). We used a journey diagram (Figure 1) to jog their memories in recalling aspects of their treatment and interactions with the cancer system and as a tool for our analysis of power and authority within the cancer care system.

Our uniquely inclusive CBPR process explicitly addressed racial equity and power sharing at each step of the project, a process described thoroughly elsewhere (Schaal et al. 2016). ACCURE's community, academic, and medical partners collaborated to develop the analysis of power and authority materials, including the journey diagram and focus group guide. Two community members were selected by GHDC as racially concordant facilitators for the focus group sessions. A person of color (Japanese-African American) facilitated sessions with Black participants at each cancer center, while a White moderator took notes. They reversed roles for the sessions with White participants. Sessions were audio-recorded and transcribed verbatim. The Institutional Review Boards at the University of North Carolina at Chapel Hill and the University of Pittsburgh approved the ACCURE study.

### Focus Group Analysis using the Analysis of Power and Authority

To analyze the data in adherence to our CBPR and antiracism principles, each step involved racially diverse community, academic, and medical center partners from GHDC working together (Schaal et al. 2016). All members of the team had been through antiracism training. A Coding Coordinating Team (CCT), a subgroup of community and academic members of the GHDC that included people of color and White representatives, developed guidelines and protocols for analyzing the transcripts. To ensure that community, academic, medical,

and racially diverse perspectives were included in the analysis, volunteer coders were solicited from the GHDC membership. The CCT developed a codebook, conducted qualitative analysis training with GHDC members, and organized GHDC volunteers into diverse coding pairs who: reviewed an assigned transcript together; assigned topical codes to relevant text; and defined and assigned interpretive codes to relevant text (Schaal et al. 2016). The CCT reviewed coded transcripts, created a consolidated codebook that included topical and interpretive codes, applied these codes to all transcripts, and produced code reports of extracted text.

Informed by the antiracism framework's analysis of power and authority, the CCT reviewed these code reports to identify the pressure points encountered by cancer care patients along the cancer journey and generated a matrix for Black and White participants, respectively. This matrix provided detailed descriptions of patients' experiences on both challenging and uplifting interactions. From that matrix, the CCT literally mapped these experiences, both positive and negative, onto the journey diagram (Figure 1) as a way to visualize encounters at the systems level. Subsequently, the CCT used the patient encounter journey diagram to generate conversations first with GHDC members and ultimately with cancer center providers and staff about how these systems-level encounters did or did not exhibit transparency and accountability and what affect these experiences might have on cancer patients.

## Results

A total of 27 breast and lung cancer patients participated in eight focus group sessions. Of the 27 participants, 12 were Black and 15 were White. Table 2 shows the breakdown of the participants by race, cancer type, and cancer center.

Six overarching, interrelated themes emerged across racial and cancer groups (Table 3): (1) fear was disempowering and discouraged continuation of care; (2) uncertainty and lack of information were disempowering and hindered care; (3) trust in the medical team was crucial to continuing care; (4) communication was empowering when providers shared information and were also good listeners; (5) navigating complex, impersonal healthcare systems was often confusing, overwhelming, and disempowering; and (6) in these impersonal systems, small interpersonal interactions were enormously important in helping patients feel cared for or disregarded. When patients were asked during their focus group discussions whether they felt they were treated differently due to their race, few explicitly described experiences of differential treatment. Despite these commonalities, implicit differences emerged in Black and White participants' descriptions of their cancer care experiences and pressure points they encountered along the way. We describe these commonalities and differences across four phases of care: diagnosis, course of treatment, daily grind in a complex system, and when treatment ends. These phases were where our patients' pressure point experiences clustered. Table 3 exhibits how the six overarching themes manifested within these four encounters.

## The Diagnosis Encounter

The moment of delivery of the diagnosis of cancer is a stressful experience for cancer patients. Black and White participants in this study shared the ways they received this news at two different cancer centers. At one cancer center, this news was largely delivered in person, while at the other it was routinely delivered by telephone without regard for whether the patient was at home or work or had a supportive individual with them. The reactions of participants to these different modes of communicating difficult, life-changing news highlighted ways that patients experienced pressure points at the outset of the cancer journey. Both Black and White breast cancer patients expressed dismay when such critical information was delivered by telephone, especially at work. Receiving such news in locations or circumstances where they did not have a safe space to express themselves emotionally or a caring source of support at their side was overwhelming and disempowering. These impersonal modes of communicating critical information at the beginning of the cancer journey typify a system not accountable to patients' needs for establishing trust with the cancer care system; and exemplify how the system lacked transparency in its two-way communication by not considering how the mode of delivering critical information may impact the patients' experience in receiving that information. For the cancer centers, this represents a missed opportunity to begin establishing trust through transparency in communication and accountability for the important nature of this first communication.

**Racial Differences**—Although both Black and White patients expressed dismay at receiving their cancer diagnosis by phone, Black patients reported concerning delays in communication. For example, one Black breast cancer patient received a voice message about her biopsy results on a Friday and had to wait five days until she could speak with her provider regarding the results. Delayed information and uncertainty were exceedingly stressful for her. Another Black breast cancer patient described a delayed diagnosis because the technician administering her mammogram did not listen to her. The patient's primary care physician (PCP) found a small mass underneath the patient's right arm and scheduled a mammogram. The patient informed the technician about this mass, identified its location, and was assured that the mammography would detect a mass if present. She later discovered from her surgeon that the area of concern was not included in the field of the image, so the mammogram was negative. Subsequently, she was retested with an ultrasound-guided biopsy that ultimately confirmed the breast cancer diagnosis originally suspected by her PCP. The Black breast cancer patient described her anger about this delay in diagnosis and, therefore, treatment:

I was angry for a while because the doctor [mammography technician] that was here at [hospital]...I thought that she would've listened to me better. If...she would've listened to what I was trying to tell her about the spot here...then I probably would not have had to go through that... So, if she would've listened maybe we could've stopped it before, but she just wouldn't listen.

This patient felt strongly that her breast cancer would have been diagnosed more quickly and treated sooner if the mammography technician had listened to her and investigated her concern. Through its lack of accountability, missing the mass so that her diagnosis and



treatment were delayed, the system in effect failed this patient. The technician served as a gatekeeper whose control of the interaction (i.e., not accepting the patient's insights and communication of the issue) resulted in inadequate follow through and critical delay in diagnosis and treatment. While only two among many, these experiences demonstrate how lack of two-way transparent communication interferes with the patient-provider relationship and lack of system accountability has potentially serious consequences for patient diagnosis, treatment, and care.

### The Treatment Encounter

The issue of transparency also arose in regard to building trust and facilitating two-way communication during the course of treatment. Once diagnosed, the participants found the processes before and during treatment to be challenging and stressful due to the lack of information and uncertainties of what to expect. Patients experienced difficult treatments, which caused problematic fatigue and noxious side effects. The pressure points they described most often were interactions with physicians as gatekeepers, which either successfully facilitated care, or failed to do so. Both Black and White patients reported that the information they received was sometimes inadequate and often too overwhelming to understand clearly. In addition, pain and side effects were not always satisfactorily managed or addressed. For example, a White breast cancer patient's crippling pain was dismissed for over a year before her doctors agreed to discontinue a medication that caused her suffering. A Black participant described her skin pain during radiation treatment as follows:

And so...I had start burning real, real bad and I couldn't stand to have anything on me...so I wanted to stop, but...because of him being a nice doctor...he heard me. ...'Cause this one day I, I said 'I refuse to go'...when they called me to go I said, 'I'm not going! I'm burning.' ...And so they called the doctor down and he came and he said, 'You're a feisty little thing.' He said, 'And I'm gonna listen to you and I'm giving you a week off.' ...and when I came back...I only had three more days to go...and I was ready to...deal with it even though...it was still painful, but I was ready to deal with it.

Clear, transparent communication and careful listening on the part of the provider was essential in creating a space for patients to question, disagree, and provide input. Our participants made it clear that patients want regular, open, clear communication and to know what to expect in terms of treatment and appointment schedules. Black and White patients both described challenging interactions with doctors when they did not feel they were listened to or consulted. Pivotal pressure points and causes for distress for cancer patients included: (1) waiting and uncertainty about aspects of their treatment; (2) inflexibility in scheduled care plans; (3) lack of preparation for and communication before procedures or treatments; and (4) unexpected changes for which patients were not well informed. These pressure points are all indicators of the lack of transparency within the cancer care system.

In spite of these negative experiences, our analysis of pressure points in the cancer care system revealed that patients were grateful for the amount and quality of support from their cancer care teams. Overall, patients felt included in the decision-making process regarding their treatment. Some patients established trusting relationships with physicians, nurses, and

support staff, even to the point where the cancer care team members and the patients themselves used humor to communicate and to bring joy to an otherwise difficult situation. There were several instances where physicians used much-appreciated humor to build rapport with patients and put them at ease.

**Racial Differences**—Whereas White patients' main issues concerned not receiving adequate post-operative care information, such as reconstructive surgery information for breast cancer patients, Black patients expressed more concern about how standard procedures or the implications of procedures were not always fully explained to them. For example, they described experiencing delays in the scheduling of surgery, as well as delays in receiving pathology or staging results after a lumpectomy. Although they tried to advocate for themselves, there was no mechanism in place to ensure the system and the procedures initiated were transparent or to hold the system accountable for timely communications.

Although patients of both races at both cancer sites expressed that their pain and side effects were not always satisfactorily managed or addressed, Black patients felt particular dissatisfaction with how their cancer treatment-related symptoms were managed. Pain and symptom control were issues for Black patients in multiple settings and from multiple causes during the course of their cancer treatment. Issues mentioned by Black patients included painful venipuncture, radiation skin problems, medication side effects, and invasive un-anesthetized procedures. When they did receive information about potential side effects, some Black patients suggested, it was insufficient, inaccurate, or late, resulting in undue pain and suffering from treatable side effects.

One Black lung cancer patient described the experience:

I was disappointed mostly in the side effects...that...is the part that really got me, ...I didn't think that you could go through all of that, because, they would tell you a certain part of it...and a few other things that wasn't mentioned... They gave me some...prescription to get the right medication, but there are certain things that I called in about... they weren't givin' me the right information I needed...at the time.

A Black breast cancer patient described a particularly harsh experience:

Cause I had a boil to come up...the provider said 'let me take a look at it' and then the next thing I knew he asked for something and he immediately lanced it. He didn't prepare me. He didn't tell me what he was doing. Nothing. And I had to actually literally grab my pants because I was getting ready to cold cock him... That's how bad it was.

Insensitivity to or even disregard for patients' pain tolerance, as the boil experience suggests, has the potential to sever the patient-doctor relationship at a time when patients are particularly in need of support and empathy. Failure to prepare patients for procedures and treatments led to excess pain and unmanaged side effects among Black patients. The lack of transparency manifested in these experiences disempowers and discourages patients, increasing the potential for discontinuation of care.



Although it is important to acknowledge how individual interactions between patients and providers influence patient health outcomes, it is critical to understand these interactions from a systems perspective. For example, the inflexibility of the protocols and procedures for scheduling surgery/treatment appointments and managing pain and symptoms reflect the failure of the *system* to maintain the transparency necessary for optimal care. Patients' experiences during treatment played a critical role in how and when they followed their treatment plan. Racial differences that emerged from our analysis of the system suggest that some Black patients were not receiving the care they needed in a timely or sensitive manner.

### The Encounter of the Daily Grind of Navigating the System

Navigating a large, complex, impersonal system without clear mechanisms for transparency and accountability was overwhelming and disempowering for the participants. Challenges faced by participants included medical and non-medical issues reflecting a lack of transparency, such as: (1) not having well-coordinated care, which led to confusion about which provider to call for which issues; (2) problems with acquiring information or support from billing offices; and (3) lack of support from social workers even in times of dire need for transportation, financial, or psychosocial support. Furthermore, these patients' challenges were a reflection of how the cancer care system can provide uneven, haphazard care. Some patients shared how they were not aware that educational and social support resources were available at their cancer center, while others had been connected with an array of resources and services. Although communication was clear at times, it was not always transparent, and the mechanisms in place did not hold the system accountable. Breast cancer participants provided one example of how such differential access to resources was experienced by patients. Some told of receiving a '*black bag*' full of breast cancer resources and information at the onset of diagnosis, while others had never heard of or been offered such a resource.

Another dominant theme among the participants was the importance of small interpersonal interactions. Participants acknowledged the crucial role their physicians played in encouraging them to initiate or continue treatment. Patients valued their interactions with staff and described them as '*welcoming*' and '*like old friends*' who '*knew their names*.' A Black lung cancer participant summed up the kind of experience expressed by participants:

So...between the cancer center, the therapist that they have there...the smallest person, even the greeters when you come in the door...they go above and beyond their job. Because I think you have to be a special kind of person to work there, you just can't be like a regular doctor's office, because they are compassionate, they understand people are going through some serious stuff, mentally, physically, and emotionally.

Despite these positive interactions, both Black lung and White breast cancer patients also described negative experiences with nursing staff and oncologists at both cancer centers. Seemingly minor interactions were perceived as critically important in making patients feel comfortable, encouraged, or empowered. Both Black and White patients gave examples of the challenges they encountered, for example, in negotiating the financial/ billing system. Patients also described stress-inducing experiences with the oncology center, including long initial visits, lack of return calls from the scheduler, and difficult interactions with '*rude*'

staff or a doctor who had no *'bedside manner.'* Patients recognized during those encounters that the quality of care was sub-optimal but did not know who was in charge or where to voice a complaint. The mechanisms for accountability of the system to the patients were not clear. A White breast cancer patient described the frustration of such an interaction she had at the front desk:

...And I actually left here in tears one day because of the rudeness of the people that worked here. It wasn't the nurse, it was like mainly the...people at the desk... and I don't know whether it was a bad day, it was just everyone was so rude. And I felt that, well you know I thought it was unprofessional, but you know if any place where you need to be kind and caring, it should be here because not only are the patients under a lot of stress, but their families are under stress. And I actually did call somebody about this and reported it.

Similarly, a Black breast cancer patient described a pressure point encounter with a White woman at the front desk:

I could get food down more and better than I had. But...there was another woman that told me about the mints and the...Lemonheads...up there at the chemo place. And when I come in there for my treatment...I would grab a handful and throw them in my purse. There was this one lady up there at that desk, she knew I was coming. Every time I came she would move 'em... And I asked her where's the Lemonheads at? {imitating lady at front desk} 'Oh, they haven't put any out today.' ...She was at the front desk on floor three. ...I went back to where the chemo people were, they always had their Lemonheads out, so I grabbed a handful of them... But for her to move them Lemonheads that really like, just took me...

**Racial Differences**—The examples above speak to individual incidences experienced by both Black and White patients. While these occasional negative experiences were dwarfed by the participants' overall positive impressions of the cancer centers, the tenor of incidents described by Black participants raise questions about whether innocuous interactions may be related to unconscious bias (Hall et al. 2015; Nolan et al. 2014; Burgess et al. 2006), a critical underpinning that may affect the quality of patient care. Whereas the White patient experienced a kind of universal rudeness from the front desk staff, the Black patient experienced a very targeted and intentional denial of a small bright spot in her chemotherapy treatment experience. While she did not explicitly describe this as an example of when she was treated differently due to her race, it emerged from our analysis as a potential racial microaggression. Microaggressions, or 'brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color,' (Sue et al. 2007, 273) could affect patients' treatment experiences whether or not they recognize them as racially-motivated. The very staff members whose role was to facilitate the patients' care journey were in fact preventing patients from progressing smoothly through the system; an example of how a gatekeeper controlling access to resources and procedures can affect the quality of care and patient experience. Moreover, each patient's response raises interesting questions about who feels empowered within the cancer system. In this case, the White patient felt empowered enough to complain and report the rude behavior. The Black patient

acknowledged that she found this behavior distressing, but she did not describe taking any action. From our antiracism lens, these encounters suggest the privilege a White patient may feel (and the reluctance a Black patient may feel) in challenging the negative treatment within a system that is not accountable to all of its patients.

In a few cases, cancer treatment-related side effects were so severe that patients reported going to the emergency department (ED) to seek care. Navigating the ED system was frustrating for cancer patients, especially the Black patients who reported more negative experiences. Black breast and lung cancer patients reported receiving inadequate information and care from the ED medical staff. There was a lack of coordination and transparency between the ED triage and the cancer care system. One Black lung cancer patient said that he was told to go to another section of the hospital after reporting to the ED located near his cancer center. Unlike a White patient who described feeling empowered during her ED visit, a majority of Black patients spoke about their experiences in the ED as a challenging and frustrating aspect of their cancer journey because they were not able to navigate the ED to receive the care they needed to manage residual pain from cancer treatment. They felt they were given insufficient treatment that only temporarily managed their pain. When they were told to schedule visits with their cancer care teams, it felt like a dismissal since it was not clearly communicated that this was the path to long-term pain management resolutions.

Navigating the cancer center system is a difficult journey for many patients, so the guidance and service that patients received from oncology and other hospital staff had a powerful effect on their overall experience. Many patients expressed how attentive and caring the cancer center staff was, while others, particularly Black patients, shared incidents of microaggressions that left them feeling disempowered by the very gatekeepers who were in place to assist them. This attests to the need for cancer center staff to engage positively with patients and for systems to be in place so that when patients, regardless of race, do not feel welcomed, respected, or well supported, they know where to go to address those issues.

### **The Encounter When Treatment Ends**

The participants' cancer-related experiences extended beyond their cancer care team since they often interacted with other areas of the hospital post-treatment, including the ED, radiology, and support groups. There were reports from both Black and White patients about positive experiences they had with receiving a post-treatment MRI (magnetic resonance imaging) and visits to the ED. One White patient emphasized how empowered she felt when she received the care she needed in the ED. A Black patient shared that she was able to advocate for herself in the ED when she insisted that the medical staff not use the port, which had been inserted for use during her cancer treatments. Another Black patient reported how appreciative she was when the person conducting her X-rays allowed a break in the scan to increase her comfort.

Yet, several patients felt the strong support they received during treatment completely dissipated once they finished their chemotherapy or radiation. This left patients feeling abandoned and ill-prepared to navigate the post-treatment issues they experienced, such as continued radiation-induced skin changes, side-effects from anti-estrogen medications, and persistent residual effects of chemotherapy. Post-treatment care was a major concern for

Black and White breast cancer patients. Patients found the system was not set up to provide continuing transparent communication after their active treatment ended, although they were expected to attend scheduled follow-ups. As one White breast cancer patient explained, *'When treatments end, the support ends.'* In the same regard, a Black breast cancer patient shared:

If I had to change something or suggest a change, it would be after treatment. I found that to be very difficult. Matter fact I fell apart... After treatment it's like what do you do? Where do you go? ...And some real high anxiety like over-the-chart anxiety issues came up after my treatment. Just like out of nowhere, which I later found out it was very typical, very normal, but I'm like I didn't know what to do... And so it wasn't until I saw...the [physician assistant] that you know if it's certain things you just call the center... You know if you got a headache, your leg hurt, your head you know go to my primary physician. But anything else so...I'm still not real clear on that.

This uncertainty about whom to contact (e.g., primary care or cancer care physician) to address post-treatment medical needs left many patients confused about who should be their primary provider following completion of cancer treatment. At one cancer center, patients mentioned that chemotherapy classes were offered. They appreciated these classes because they provided information about what to expect during treatment. Patients desired to have similar resources that offered more widespread support post-treatment. They desired reliable sources to contact to address their questions and to assist them with navigating the medical system after the completion of active cancer treatment.

The care of cancer patients extends beyond the actual cancer center. Patients need flexible and compassionate care from gatekeepers in all sections of the hospital that they interact with. Even after the patients' care plans have been completed, they experience residual medical issues for weeks or months related to their cancer treatment. All cancer patients need well-defined instructions on steps to take when they have pain or symptom management concerns after treatment ends.

## Discussion

Our analysis of power and authority focus group findings provide important considerations for how cancer centers in the US can improve transparency and accountability for quality and completion of treatment within their system. As one patient eloquently described the challenges of navigating the cancer system for her treatment and care, *'it's like you don't have a roadmap really.'* Our findings shed important light on what the experience of treatment was like for cancer survivors and suggest critical areas where cancer systems could change their procedures and policies, as well as better educate and prepare gatekeepers, to improve care for all patients. As described by our patient participants, most of the pressure point encounters were related to lack of transparency, such that improvements in communication, particularly two-way communication could greatly improve patients' interaction with the system. Pathways for accountability can also be built into a system that allows patients to find solutions for their problems with the system itself. Seen through an antiracism lens, the experiences these participants shared about their

diagnoses, treatments, and dealings with complex cancer centers suggest eight patient-centered systems-level interventions that could address common pressure points and potentially improve cancer center experiences for all patients:

- (1) Participants said learning of their diagnosis was enormously stressful. The stress was intensified for those who had received the news by telephone, because it was impersonal, and did not allow for the opportunity to absorb information or formulate questions. Following-up with patients in person after diagnostic imaging and procedures would address this problem.
- (2) Some participants found a first visit with a multi-specialty oncology clinic to be informative, streamlined, and reassuring, but others found that approach overwhelming because of the length of the visit and the sheer amount of information conveyed by multiple providers. Centers might offer options for the first visit format based on patient preferences.
- (3) Systematizing provision of informational resources, triaging for social service needs at regular intervals, and documenting these interventions in the electronic health record could help to ensure every patient has access to needed support services.
- (4) While reducing wait times might be difficult, appointments might be made less stressful by allowing patients to wait in common spaces, rather than in gowns in exam rooms.
- (5) Our participants reminded us that procedures clinicians consider minimally invasive are often aversive experiences for patients. Protocols that limit venipuncture attempts and appointment systems whereby patients might have their intravenous lines placed or indwelling catheters accessed by known, trusted phlebotomists and nurses might reduce the distress associated with these procedures.
- (6) Protocols for timely communication among ED staff, on-call oncologists, and patients might alleviate some of the stress associated with unexpected complications that result in visits to the ED.
- (7) Health systems can establish clear protocols to communicate the plan for follow-up or identify community resources for survivorship education and support for every patient transitioning out of active treatment. Our participants' concerns align with a growing conversation about the need to provide survivorship care plans for all patients that are post-treatment.
- (8) Finally, consistent policies that *explicitly* address the mechanisms patients have to address institutional problems should be clear. Guiding patients through the system with accessible policies will clearly establish the institution's commitment to accountability to patients.

Our findings have been crucial to informing ACCURE's groundbreaking intervention components and to engaging cancer center providers and staff in the effort to increase their own cancer care systems' mechanisms of transparency and accountability. Using the

analysis of power and authority tool for this formative research also emphasized the importance of using an antiracism lens to understand and intervene on racial inequities in health. In order for this type of analysis to be effectively used, community and academic researchers must gain the shared understanding, language, and lens offered by an antiracism training to fully comprehend and appropriately apply the analysis of power and authority to research. Efforts should be made to increase access to antiracism trainings to enable more researchers to learn about this framework for examining systems. A limitation of this formative study is our findings are specific to the care systems at two cancer centers and may not be transferrable to other cancer centers. Nonetheless, our two partnering cancer centers were specifically selected as ACCURE sites to reflect a range of cancer centers in the US (i.e., those that are affiliated with regional hospitals and academic medical centers), as well as the racial gap in patients' outcomes exhibited in cancer centers across the country (DeSantis, Naishadham, and Jemal 2013; Samuel et al. 2014; Lathan, Neville, and Earle 2008; Keating et al. 2009; Smith, Earle, and McCarthy 2009; Cykert et al. 2010; Farjah et al. 2009). Hence, our findings are likely relevant to other cancer centers.

A major strength of this formative research is the central role that our community partners in the GHDC played in holding academic and medical center partners accountable and transparent throughout the research and intervention process. The GHDC members led the effort to pinpoint pressure points that might be related to differential treatment by race, discussed preliminary findings, and once the findings were finalized, suggested ways to incorporate them into the larger project, fine-tune ACCURE navigators' work goals, and shape content of the Healthcare Equity and Education Training sessions for cancer center providers, staff, and administrators. Another strength is that our team included cancer survivors whose perspective was essential, and feedback was taken into account at every step of the research process. Our CBPR approach to planning, data collection, analysis, interpretation, and writing of this manuscript integrated multiple perspectives throughout the process, including Black and White cancer survivors, community members, healthcare workers, and academic researchers.

Our analysis of power and authority of the cancer care system has shown that:

- (1) There are several key pressure points along the cancer care continuum where patients encounter barriers to care and feel disempowered. These pressure points are where the healthcare system can be improved to facilitate more empowering experiences for patients.
- (2) The Undoing Racism<sup>®</sup> framework's analysis of power and authority serves as an effective tool for analyzing pressure point encounters and identifying equity issues within the healthcare system.
- (3) The concepts of transparency and accountability provide a starting point for the fields of public health and medicine in general, and cancer health disparities in particular, to understand and address how structural issues contribute to persistent cancer disparities.

In sum, our findings from patients' encounters with the cancer care system underscore the need for new ways to ensure transparency and accountability for cancer care through clear,



two-way communication systems and well-integrated policies and procedures that serve as a roadmap to guide patients, clinicians, and staff through the cancer care journey. The use of the antiracism framework to achieve systems change may assist in eliminating Black-White inequities in the quality and completion of cancer treatment.

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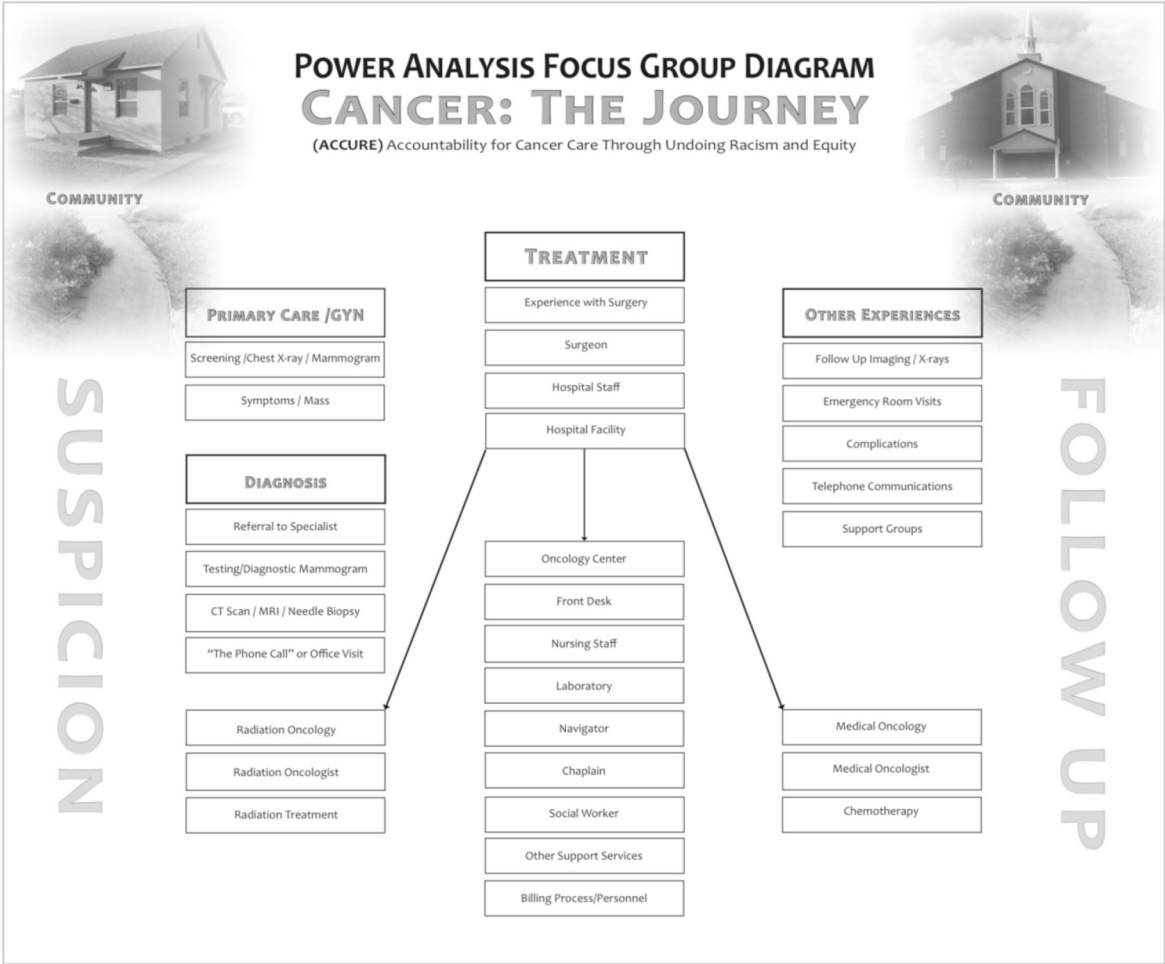
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**Figure 1.**  
Cancer Journey Diagram<sup>a</sup>  
<sup>a</sup>The cancer journey diagram, developed by GHDC and Sisters Network Greensboro NC, a local affiliate of a national African American breast cancer survivorship organization, was a focal point for analysis of power and authority discussions and data analysis. It depicts a patient’s journey through cancer care, beginning in the community, from diagnosis through therapy and return to the community following treatment.

Table 1.

## Analysis of Power and Authority Focus Group Guide

#	Question and Additional Prompts
Introduction	We've put together this diagram to jog memories of the 'journey through the cancer care system.' Each person's journey is a bit different, but we can hopefully use this as way to remind us of all the different parts of the system. You can also let us know as we go along if we need to change or add anything to this diagram to better reflect the treatment experience at your cancer center.
1	We can start with a quick walk through the diagram to review the many important points in a cancer treatment process. We show progression from initial testing through diagnosis to the cancer center and through treatment. At each point there are multiple medical and non-medical experiences that can influence the quality of your experience. For example, I would like to hear your experiences with services, paper work, unfamiliar medical vocabulary, rules and regulations, schedules, preparation and follow-up procedures, or experiences when medication side effects may not have been explained. There may be: <ul style="list-style-type: none"> <li>• Points (encounters with the medical system) where you felt 'stuck'; that you did not know how to move forward in the system</li> <li>• Points where you were sent 'back and forth'; or going in circles like a merry-go-round</li> <li>• Points of particular confusion</li> </ul> {STOP to allow time for the participants to add to the diagram and reflect on these points.}
2	Now that we've got the system mapped out and you are thinking about your experiences, let's begin by describing: <ul style="list-style-type: none"> <li>• What led you to start your cancer treatment at your cancer center instead of another place?</li> <li>• What made it easy or hard for you to DECIDE to start your treatment at your cancer center?</li> <li>• And then, tell me about particular points in this journey, or situations, where you felt EMPOWERED (meaning that you fully understood the plan, your opinions were respected, that you were a full partner in your own cancer treatment)?</li> <li>• What about that experience made you feel empowered?</li> </ul>
3	And what about experiences in the journey or situations where you did NOT feel EMPOWERED / that you were a full partner in your own cancer care? <ul style="list-style-type: none"> <li>• What about that experience made you feel disengaged, discouraged, and/or disappointed?</li> </ul>
4	Tell me about times when you felt you had a part in making decisions about your care. <ul style="list-style-type: none"> <li>• How was your participation 'invited'?</li> <li>• How welcome do you think your participation was in that instance?</li> </ul>
5	And what about times when you felt you were NOT allowed to participate in making decisions about your care? <ul style="list-style-type: none"> <li>• What happened to make you feel like you weren't allowed to participate?</li> <li>• Were there times when you did not feel welcome to participate in decision-making but you did/tried to participate anyway? What happened?</li> </ul>
6	Were there any incidents or points along this journey that made you want to stop treatment? Tell me about that... <ul style="list-style-type: none"> <li>• Did you tell any medical staff that you wanted to stop treatment? What happened?</li> <li>• Why did you decide to continue?</li> <li>• How do you think the cancer care system should handle issues like this?</li> </ul>
7	Describe any incidents or points along this journey that really built up your courage to continue your care. <ul style="list-style-type: none"> <li>• Tell me more about that...</li> </ul>
8	Were there barriers to YOU for getting the best care? <i>(Give a long pause for silence to wait for answers before giving these examples: any challenges regarding paper work, unfamiliar medical vocabulary, rules and regulations, schedules, preparation and follow-up procedures.)</i> Tell me about those. <ul style="list-style-type: none"> <li>• Did you know of anything or anyone in the cancer center system that might have been able to change that situation?</li> <li>• How were those barriers dealt with, or were they?</li> </ul>
9	Do you feel you were treated differently (positively or negatively / better or worse) because of your race or other elements of your cultural or ethnic background? If so, what gave you this feeling or impression?
10	What was helpful to you in getting the quality of care YOU needed? <ul style="list-style-type: none"> <li>• What was helpful about the way the procedures/services were organized?</li> <li>• How did this help you?</li> </ul>
11	What were the points in this system that made your experience especially difficult or frustrating? <ul style="list-style-type: none"> <li>• (If answers are personal—family, relationships, work, etc.) Did you know of anything or anyone in the cancer center system that might have been able to help with that situation, or anyone you could go to for advice?</li> <li>• Did you communicate these struggles to your providers? How?</li> </ul>
12	Based on your experience with cancer diagnosis and treatment system, if you had the power to improve the system, what would you change?

**Table 2.**

Analysis of Power and Authority Participant Profile By Race, Cancer Type, and Cancer Center

<b>Race</b>	<b>Cancer Type</b>	<b>Cone Health Cancer Center (Regional Hospital)</b>	<b>UPMC Hillman Cancer Center (Teaching Hospital)</b>
Black	Lung	3	1 <sup>a</sup>
	Breast	4	4
White	Lung	5	1 <sup>a</sup>
	Breast	5	4

<sup>a</sup>Conducted as one-on-one in-depth interview using the same focus group questions

**Table 3.**

Encounters in the Cancer Care System Where the 6 Overarching Themes Manifested

THEMES	ENCOUNTERS			
	<i>Diagnosis</i>	<i>Treatment</i>	<i>Daily Grind</i>	<i>Treatment Ends</i>
<b>1: Fear</b> was disempowering and discouraged continuation of care	X	X	X	X
<b>2: Uncertainty</b> and lack of <b>information</b> were disempowering and hindered care	X	X	X	X
<b>3: Trust</b> in the medical team was crucial to continuing care		X	X	
<b>4: Communication</b> was empowering when providers shared information and were also good listeners		X	X	
<b>5:</b> Navigating complex, <b>impersonal</b> healthcare systems was often confusing, overwhelming, and disempowering	X	X	X	
<b>6: Small interpersonal interactions</b> were enormously important in helping patients feel cared for or disregarded	X	X	X	

# **EXHIBIT B**

## A Multi-Faceted Intervention Aimed at Black-White Disparities in the Treatment of Early Stage Cancers: The ACCURE Pragmatic Quality Improvement Trial

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## ABSTRACT

Reports continue to show that Black patients with curable lung or breast cancer complete treatment less often than similar White patients resulting in worse survival. The Accountability for Cancer Care through Undoing Racism and Equity trial was designed as a pragmatic, quality improvement trial comparing an intervention group to retrospective and concurrent controls in an effort to reduce treatment disparities. Patients with early stage breast or lung cancer aged 18 to 85 were enrolled (N = 302) at 2 cancer centers between April 2013 and March 2015 for the intervention component. Data from patients seen at these sites between January 2007 and December 2012 were obtained to establish baseline completion rates. Concurrent data for non-study patients were used to monitor for any secular trends. The intervention included: a real time registry derived from electronic health records to signal missed appointments or unmet care milestones, a navigator, and race-specific performance feedback. The primary outcome was “Treatment Complete”, a composite variable representing completion of surgery, recommended radiation and chemotherapy for each patient. The mean age in the intervention group was 63.1 years and 37.1% of patients were Black. Treatment completion within retrospective and concurrent controls showed significant Black-White differences (Blacks (B) 79.8% vs. Whites (W) 87.3%,  $p < 0.001$ ; 83.1% B vs. 90.1% W,  $p < 0.001$ , respectively). The disparity was much smaller within the intervention (B 88.4% and W 89.5%,  $p = 0.77$ ). Multivariate analyses confirmed the reduction in treatment gap. The odds ratio (OR) for Black-White disparity within the intervention group was 0.98 (95% CI 0.46 – 2.1); between group analyses showed Black completion in the intervention compared favorably to Whites in both the retrospective (OR 1.6; 95% CI 0.90 – 2.9) and concurrent (OR 1.1; 95% CI 0.59 – 2.0) groups. We conclude that a system-based intervention consisting of a real time registry combined with feedback and

navigation improved completion of cancer treatment for everyone and narrowed Black-White disparities.

Keywords: cancer disparities; institutional racism; intervention; quality improvement

## 1.0 INTRODUCTION

Inequalities in the treatment of early stage breast and lung cancer have been consistently documented for Black patients compared to similar White patients for decades<sup>1-4</sup>. These treatment differences are extremely important because lung cancer is the leading cause of cancer death for both men and women<sup>5</sup> nationally and breast cancer is second to only lung cancer in women<sup>5</sup>. While Bach and Hershman demonstrated a direct contribution of disparities to excess mortality for Blacks more than a decade ago<sup>1,2</sup>, recent data show that lung cancer survival disparities persist while breast cancer survival disparities have actually widened<sup>6</sup>. Even after controlling for confounders, such as comorbidity, health insurance, and socioeconomic status, studies still report less care and increased mortality for Blacks<sup>1,2,7,8</sup>. Factors such as implicit bias, mistrust, and poor communication have been associated with treatment variability<sup>4,9-11</sup> but interventions to address these issues have been sparse<sup>12,13</sup>. In response to these gaps in research and persistent unequal outcomes, the Greensboro Health Disparities Collaborative (GHDC), the UPMC Hillman Cancer Center, the University of Pittsburgh School of Medicine, Pittsburgh Pennsylvania, and Cone Health Cancer Center, Greensboro, North Carolina joined together to test a system change intervention to enhance racial equity in the completion of cancer treatment. We conducted a trial, Accountability for Cancer Care through Undoing Racism and Equity (ACCURE), using a multi-faceted intervention designed to address barriers identified in our preliminary studies and informed by community-based participatory research. In this report, we describe the intervention and the clinical results.

## 2.0 MATERIALS AND METHODS

### 2.1 Study Design and Intervention

We performed a 5-year study to examine the effect of an intervention on disparities in treatment completion for Black patients with stages 1 and 2 lung or breast cancer compared to similar White patients. Our study was a pragmatic trial as assessed by the PRECIS-2 definition<sup>14</sup>; specifically, the patients were community based with broad enrollment criteria, treated by usual care providers in a typical cancer care setting using tools and personnel that could easily fit into routine clinic workflows. Study diagnoses were selected because of our community partners' awareness that these cancers were very common and often fatal among people in their communities with similar racial and socioeconomic backgrounds.

The ACCURE intervention study utilized the People's Institute for Survival and Beyond (PISAB) Undoing Racism™ framework as a conceptual model for medical care. Recognized by the Aspen Institute (2004) as one of the top 10 anti-racism training programs in the U.S., the PISAB Undoing Racism™ framework suggests that the world is controlled by powerful systems with historically traceable roots. Once people are shown how they benefit from or are oppressed by those systems, they can work together and lead system change. Therefore, transparency in measuring system effects and accountability to implement change become the key concepts for undoing institutional racism and establishing racial equity<sup>15</sup>. In this vain, all consented patients received the intervention which consisted of a real time warning system derived from automated uploads of data from electronic health records (EHRs) to enhance transparency, feedback to clinical teams on completion of cancer treatments according to race (enhance both transparency and accountability), and a nurse navigator with access to the warning system (to formalize accountability). Health equity training sessions covering concepts such as implicit bias,

gatekeeping, and institutional racism were offered to all staff and providers quarterly to make them aware of these concepts. See Figure 1 which demonstrates the relationship of the real time registry derived from EHR downloads leading to transparency of substandard or delayed care within a window of actionable intervention connecting to the accountability provided by the interactions of the navigator and physician champion with patients and the relevant clinical team resulting in quality improvement for all.

Because of the ubiquitous nature of EHRs and the pervasiveness of quality improvement (QI) work in practice, we felt it was unethical to randomize patients to a “control” group devoid of data feedback and electronic tools so we used a QI approach. We established 2 statistical control groups. The first group included all patients diagnosed with stages 1 and 2 breast cancer or non-small cell lung cancer at UPMC and Cone from January 1, 2007 to December 31, 2012 to establish baseline treatment completion rates and racial differences. The second control was the concurrent population of stage 1 and 2 breast and lung cancer patients who were diagnosed in 2014 and 2015 and not enrolled in the intervention. The latter group ensured that improvement documented in the intervention did not represent spontaneous improvement in the participating centers thus eliminating the possibility of secular trends. Variables collected in all groups included site, gender, age, race, health insurance status, marital status, zip code, cancer stage at diagnosis, and co-morbid illnesses. We recorded whether patients received surgical treatment, radiation therapy (and dose), or chemotherapy (and number of treatments) and the dates of all treatments. Within the intervention group, we conducted a small, pre-planned randomized trial in which half received standard nurse navigation consisting of nurse availability for patient initiated contacts on an as needed basis and half received a specially trained nurse navigator who attended a racial equity training delivered as a 2 day workshop by the Racial Equity Institute (Greensboro,

NC) that included components on the culture and history of racism, institutional aspects of racism, the role of implicit bias, and systematic approaches to establish “anti-racism”. These special navigators also received case-based training on barriers more specific to the Black community such as medical mistrust, lack of self-efficacy, poor communication, and beliefs that negatively influence care (e.g. “air will cause the spread of cancer during surgery”). This latter training was delivered by one of the principal investigators (Cykert) during two 1-hour sessions during the first 3-months of recruitment and was based on findings of a prospective cohort study that explored factors leading to disparities in receipt of lung cancer surgery<sup>4</sup>. The special ACCURE Navigator protocol was proactive and not dependent on patient initiation. It required 2 navigator initiated face-to-face meetings within the first month of diagnosis; then monthly contact was scheduled, usually by telephone, to assess progress in addition to any patient initiated communications. The real time registry system generated reminders for these visits until the visit was documented by the navigator. These meetings occurred for all patients randomized to the special navigator regardless of patient race. A priori, we estimated that by enrolling 270 patients (162 White and 108 Black) that we had 80% power to detect a treatment completion difference of 14% in the special navigator group above usual care navigation.

Other important features of the intervention are described. For the real time registry, we received automated nightly uploads of EHR data including patients’ appointments for clinician visits, tests, treatments, and procedures. The registry was configured to deliver alerts when a patient either missed a scheduled appointment or did not reach an expected milestone in care. Programmed milestones were determined a priori with cancer center clinicians and are shown in Table 1. To monitor intervention fidelity, we logged all warnings and navigator responses in the registry system.

For each cancer center, we selected a practicing oncologist to serve as the ACCURE physician champion. The champion made other clinicians and staff aware of the study through scheduled staff meetings and was responsible for delivering quarterly reports that included surgical rates and completion rates for chemotherapy and radiation therapy of the cancer center population and intervention group stratified by race. Note that the study team did not determine whether actual initiation of adjuvant chemotherapy was appropriate. Once chemotherapy was started the number of completed cycles were ascertained again through automated EHR uploads. We assumed that all patients who received breast conserving surgery (BCS) should start and complete adjuvant radiation.

## 2.2 Patient Enrollment

Patients with the new diagnosis of stage 1 or 2 breast or lung cancer between the ages of 18 and 85 were eligible for intervention. Exclusions included pregnancy, inability to speak English, and cognitive impairment. Enrollment occurred from April of 2013 until March of 2015. Our goal was to recruit consecutive patients at the participating centers as quickly as possible so that everyone experienced 2 to 3 years of follow-up. To identify eligible patients, research assistants (RA) screened patient schedules from breast surgery, thoracic surgery, oncology, pulmonary, and multi-disciplinary cancer clinics. All these schedules were available through the EHR. Most patients screened were not eligible because of a non-cancer diagnosis, a follow-up visit rather than an initial diagnostic visit, a cancer diagnosis other than breast or lung, or a stage more advanced than stage 2. See Figure 2 for a schematic representation of enrollment. The top row of this Consort diagram represents all the patients screened regardless of eligibility. The second row shows the number of eligible patients identified by race and those refusing consent. When



eligible patients shared simultaneous appointment times, RA's were trained to prioritize Black patients for enrollment as a method of oversampling. Informed consent was given by all participants. Institutional Review Board approval was obtained from each study institution. ACCURE was registered with ClinicalTrials.Gov (NCT01954641).

### 2.3 Primary Outcome

The primary outcome reflecting a full course of treatment for both cancers is the composite, "Treatment Complete". Treatment Complete is defined: (1) for lung cancer, a patient must receive resection surgery or a full course of stereotactic radiation calculated for potential cure. If chemotherapy was started for stage 1B or stage 2 patients, then administration of at least 3 of 4 cycles had to have occurred to be deemed complete. (2) For breast cancer, any patient who did not undergo surgery received a, "no" for Treatment Complete. If surgery was BCS, then adjuvant radiation had to be completed. If chemotherapy was initiated either in the setting of complete mastectomy or BCS plus radiation, then a patient must have received at least 4 cycles.

## 3.0 THEORY / CALCULATION

Patient characteristics including gender, age, median household income by zip code, race, and marital status were summarized using descriptive statistics and compared across study groups and within study groups between races using chi-square and F-tests for categorical and continuous variables, respectively. Since we were interested in estimating treatment completion differences between Black and White race for each study group, a logistic regression model including a combination of study group and race variables was used to estimate treatment

completion percentages and differences in treatment completion percentages for each study group by race. The retrospective data were used to define baseline treatment disparity between Black and White patients. Concurrent data were used to assess the disparity during the intervention period and therefore assess secular trends or spillover effects for non-enrolled patients. In order to control for bivariate differences across study samples and between races within each study sample, a similar logistic regression model that included age, marital status, health insurance status, median household income, study site and Charlson Comorbidity Score in addition to study group by race combinations was employed to estimate differences in treatment completion between Black and White patients within each study group. Subsequently, using the same model and data from all 3 study groups, we compared estimates of racial differences between baseline (retrospective) and intervention and between concurrent and intervention study groups to further assess effectiveness of the intervention.

#### **4.0 RESULTS AND DISCUSSION**

During the recruitment period, 132 Black and 265 White patients eligible for the study were identified and 92.4% and 77%, respectively, agreed to participate. Ten Black (8.2%) and 18 White (8.7%) patients withdrew prior to ascertainment of clinical outcomes and were removed from the analyses. See Figure 2. For characteristics of the 3 study groups, see Table 2. Black patients in the intervention group were intentionally oversampled. Patients in the intervention group were older, had less private insurance, and there were proportionally more males and fewer married individuals than in the other cohorts.

The unadjusted rates for Treatment Complete in the retrospective group were 79.8% for Black patients (B) and 87.3% for White patients (W), ( $p < 0.001$ ); in the concurrent group treatment

completion rates also significantly favored White patients – 83.1% B vs. 90.1% W, ( $p < 0.001$ ) – suggesting persistence of disparities. In contrast, Black patients in the intervention group achieved a Treatment Complete rate of 88.4% compared to 89.5% for Whites ( $p = 0.77$ ). Bivariate comparisons within the retrospective and concurrent whole population groups showed that in addition to Black race, lower median income, a lack of private insurance, and being unmarried were associated with lower treatment completion. Within the intervention group, these variables were not associated with significant treatment differences. For the intervention, Site 1 had a completion rate of 88.3% compared to 91.0% for Site 2 ( $p = 0.44$ ). See Table 3 for full bivariate results.

Multivariate analysis within study groups confirmed reduced treatment completion for Black compared to White patients for the retrospective (OR 0.79; 95% CI, 0.65 – 0.96) and concurrent control (OR 0.69; 95% CI 0.49 – 0.96). There was no Black-White disparity demonstrated within the intervention group (OR 0.98; 95% CI 0.46 – 2.1). Between group comparisons using the combined model examining race-group interactions showed completion rates for Black patients in the intervention compared favorably to Whites in the retrospective group (OR 1.6; 95% CI 0.90 – 2.9) and the concurrent group (OR 1.1; 95% CI 0.59 – 2.0). Patients without private insurance and unmarried had lower completion rates in the overall model and a site effect was noted (See Table 4).

The small randomized study within the intervention cohort did not show a statistically significant difference in favor of the special navigator (91% vs. 87%,  $p = 0.38$ ).

Fidelity monitoring for the real time registry revealed 3,340 missed appointment warnings; all but 45 were resolved through appointment rescheduling and completion. 111 milestone warnings were triggered; 59 were resolved by achieving treatment completion. Nineteen of these missed

milestones were for “no lung cancer surgery in 130 days” but these actually represented patients who received definitive treatment with stereotactic radiation and completed treatment. Therefore, 40 warnings did not lead to advancements in care.

When interpreting the results of ACCURE, some of the history concerning racial disparities must be considered. As noted by the Sullivan Commission (2004)<sup>16</sup>, the more visible racial barriers of the U.S. health care system were eradicated by the Civil Rights Era, but today’s effects from “institutional racism” are subtle. Institutional racism has been defined as a process of oppression, unconscious or not, functioning as “a system of structuring opportunity and assigning value based on race phenotype, that unfairly disadvantages some and undermines the potential of the whole society”<sup>17</sup>. Examples include: lack of providers within reasonable traveling distance, poor institutional understanding of how to mobilize community organizations that principally serve Black residents, and racial discordance between patients and clinicians that may affect care-seeking behaviors<sup>18-20</sup>. Our previous work demonstrating that Blacks with higher comorbid risk, poor perceptions of communication, or no regular source of care were less apt to receive cancer surgery served as a poignant example of how unintended, institutional biases can be operationalized<sup>4</sup>.

Given the many factors contributing to treatment disparities and lack of data supporting a single intervention, the research team and community partners determined that a multi-faceted approach utilizing transparency of clinical data and care team accountability achieved through race-specific audit and feedback was required for the highest probability of success. With the diffuse prevalence of EHRs since passage of the HITECH Act of 2009, we hypothesized that digital data available at nearly all cancer centers could rapidly populate a real time registry and generate warnings providing the transparency needed to identify barriers to treatment completion

whether attributable to patient factors (e.g. missed appointments) or clinical inertia (e.g. unmet milestones in the context of appointment adherence). Bickell et al. previously demonstrated that a registry could narrow undertreatment disparities for adjuvant breast cancer care intended for Black and Hispanic patients<sup>12</sup>. Their registry was populated with hand entry by RAs who called the offices of patients' providers including surgeons, oncologists, and primary care physicians asking about consultations obtained and adjuvant treatments started. These tedious steps were followed by supplemental, manual chart reviews. Similar "hand-entered" systems would be untenable as a population-based, real time tool. The system built for ACCURE mimicked the treatment categories of the Bickell intervention but accomplished this in a fully automated manner translatable to widespread use. Given the demonstrated effectiveness of QI approaches such as audit and feedback, this accountability piece was added<sup>21,22</sup>. To disentangle the structural issues of race and social class, community partners advocated making feedback race-specific. In addition, we presented the results stratified by comorbid conditions and race to address concerns about implicit bias in decision-making associated with the uneven interpretation of comorbidities highlighted in our prior work<sup>4</sup>. Lastly, given past barriers to patient adherence such as poor perceptions of communication, negative beliefs (e.g. air exposure spreads cancer), religiosity, and low health literacy, we included assessment and discussion of these issues in navigator training. Although race-related navigation has not been shown to specifically improve cancer treatment disparities, reports have described improvements in screening and diagnosis<sup>23-25</sup>. Navigation in ACCURE worked regardless of concordance in navigator-patient pairs suggesting that training related to the harsh realities and histories of the African American experience results in enhanced communication regardless of the race of the trainee. A more formal analysis of this result could be considered in future work in order to maximize the navigation effect.

As noted, all ACCURE components are supported in the literature, but which interventions really worked? An unintended limitation of the study helped answer this question. One cancer center experienced high clinician turnover mid-intervention. This turnover limited opportunities for effective audit and feedback. Despite this circumstance, improvement in the affected center was strong though not quite as robust as the second center. This result suggested high efficacy of the real time registry and the nurse navigators who acted on registry warnings. The efficacy of registry function plus navigation was further supported by the high rate of rescheduling action noted for missed appointments and the resolution of most deficient milestones in care. Regarding the health equity training sessions, if they played a major role in improvement, we should have seen a spillover effect through narrowing of racial differences in the concurrent control group. This effect did not occur.

Another important observation concerns the nurse navigators. In the small randomized portion of the study comparing navigators according to training, we saw no significant treatment completion increase favoring the ACCURE navigator compared to the usual care nurse navigator. This result could have several explanations. First, the ACCURE navigator did interact with the other nurse navigators so there could have been some adoption of ACCURE principles by the usual care nurses. Also, the ACCURE navigator did not specifically target patients of Black race, lower socioeconomic status, or low health literacy. Therefore, the effectiveness of the special training may have been diluted by including patients that didn't need more intense engagement. Conversely, it is possible that nurse navigators perform equally well when supported by real time tools that identify patients who need more engagement to complete difficult treatment regimens.

Given the shallow pool of evidence for effective system change interventions, the potential impact of ACCURE's promising results is two-fold. First, the ACCURE use of a real time registry derived from multiple EHRs can directly incorporate digital data to impact completion of important treatments. Second, race-specific feedback delivered during the actual course of care can be complementary to evolving registry systems such as the American Colleges of Surgeons (ACOS) *Rapid Quality Reporting System* and, ultimately, drive sustainable transformations within the 1,472 cancer facilities already accredited by the ACOS *Commission on Cancer*<sup>26-28</sup>. This process of systematically combining real time informatics support, data usage, and appropriate role responsibilities for using these data is crucial.

Since the time of Bach's report on lung cancer disparities, despite sharp definition of the problem and the application of individual level interventions such as culture competence education, recent data demonstrate little progress<sup>1,4,11</sup>. In fact, 2016 cancer statistics show lung cancer mortality remained 20% higher for Black than White men<sup>6</sup> and the Black-White mortality gap for breast cancer is actually widening<sup>6</sup>. Although social determinants and comorbid illness can all contribute to these survival differences, a significant part of the chasm for both cancers are directly attributable to the lack of treatment completion for Black patients. Specifically, Black lung cancer patients receive surgery and curative radiotherapy less often than similar White patients<sup>1,4,29</sup>; Black breast cancer patients undergo less surgery, radiation, and chemotherapy than White patients<sup>30,31</sup>. Even when chemotherapy is prescribed, completion rates are lower for Black women and lower completion rates are independently associated with worse survival<sup>2,32</sup>. These data make the case for systematic, practice transformation interventions like ACCURE all the more compelling.

## **5.0 IMPLICATIONS**

A multifaceted, system-based, practical intervention applied to patients with either early stage breast or lung cancer resulted in improved treatment completion for Black and White patients and reduced the racial disparity demonstrated in historic and concurrent controls. If applied broadly, this intervention could potentially improve cancer treatment and reduce disparities in over 1400 cancer centers in the U.S. As the intervention incorporates a real time electronic registry and other simple tools to promote transparency and accountability in care, future research using this approach could focus on improving treatment of cancers and common chronic illnesses with longer therapeutic horizons. Success in applying similar system based approaches to these areas of care could potentially mitigate disparities and result in substantial gains in quality of life and survival for Black patients and the population at large.



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### **Figure Legends**

Figure 1. ACCURE Conceptual Model

Figure 2. Patient Enrollment, Randomization, and Progression in ACCURE.

**Table 1. Unmet milestones used to trigger warnings in the real time registry for study patients**

<u>Lung Cancer</u>
No clinical appointment, diagnostic test, or treatment scheduled within 30 days of the index visit
No surgery or radiation scheduled within 90 days of the index visit
No surgery performed by day 130 from the index visit
<u>Breast Cancer</u>
No clinical appointment, diagnostic test, or treatment scheduled within 30 days of the index visit
No breast cancer surgery completed within 30 days of the initial visit
No chemotherapy or radiation appointments scheduled within 21 days of breast cancer surgery
No chemotherapy treatments actually received within 90 days of breast cancer surgery
No radiation treatments actually received within 90 days of breast cancer surgery

**Table 2. Characteristics of stage 1 and 2 breast and lung cancer patients by study group**

Characteristics	Retrospective Whole Population Cohort (Control Group) N = 8945 (percent, 95% CI) <sup>†</sup>	Concurrent Whole Population Cohort (Control Group) N = 2717 (percent, 95% CI)	Intervention Group  N = 302 (percent, 95% CI)
Mean Age (years)	61.7 (61.4, 61.9)	62.7 (62.2, 63.1)	63.1 (61.8, 64.4)
Female Gender	88.0 (87.3, 88.7)	89.3 (88.2, 90.5)	83.1 (78.9, 87.3)*
Married or Lives with Significant Other	60.4 (59.4, 61.4)	58.3 (56.5, 60.2)	47.4 (41.7, 53.0)*
Black Race	11.8 (11.1, 12.5)	12.5 (11.2, 13.7)	37.1 (31.6, 42.5)*
Private Insurance	51.7 (50.7, 52.8)	47.0 (45.1, 48.0)	30.8 (25.6, 36.0)*
Mean of Median Household Income by Zip Code (\$)	53.6K(53.3K,54.0K)	54.1K(53.5K,54.8K)	49.2K(47.2K,51.0K)*
Mean Charlson Score	2.8 (2.70, 2.82)	2.7 (2.55, 2.77)	2.6 (2.33, 2.97)
Clinical Stage 1 at Diagnosis	64.7 (63.7, 65.7)	64.5 (62.7, 66.3)	74.5 (69.6, 79.4)*
Breast Cancer	76.2 (75.3, 77.1)	78.0 (76.5,79.6)	59.6 (54.1, 65.1)*

\*Difference statistically significant comparing the intervention cohort to the whole population cohorts, p<0.05

<sup>†</sup>CI = confidence interval

**Table 3. Bivariate treatment completion results according to patient characteristics within each study group**

Patient Characteristic	Retrospective Whole Population Cohort (Control Group) N = 8945	Concurrent Whole Population Cohort (Control Group) N = 2717	Intervention Group N = 302
Mean Age (years)			
Treatment Complete			
Yes	62.4	62.8	62.7
No	63.7	63.2	66.5
p-value	0.004	0.59	0.07
Median Income (\$)			
Treatment Complete			
Yes	54,442	54,810	48,524
No	51,489	50,303	54,468
p-value	<0.001	<0.001	0.13
Married (% TC*)			
Yes	88.2	90.9	90.9
No	83.8	88.6	87.4
p-value	<0.001	0.05	0.33
Private Insurance (% TC)			
Yes	89.3	91.3	89.3
No	83.6	88.7	89.0
p-value	<0.001	0.03	0.95
Charlson Score (% TC)			
≤1	86.8	91.9	93.3
>1	86.1	88.5	88.4
p-value	0.39	0.005	0.22
Race (% TC)			
White	87.3	91.9	89.5
Black	79.8	83.1	88.4



TC = Treatment Complete

**Table 4. Results from multivariate logistic regression of treatment completions including all race-group combinations; within and between group comparisons are shown**

Variable	Beta	Odds Ratio (95% Confidence Interval)	p-Value
Age	0.004	1.00 (0.99, 1.01)	0.15
Charlson Score (> 1 vs. < or =1)	-0.12	0.89 (0.79, 1.0)	0.06
Median Zip Code Income	0.003	1.00 (1.0, 1.01) <sup>3</sup>	0.15
Marital Status Not Married vs. Married	-0.22	0.80 (0.71, 0.90)	<0.001
Private Insurance No vs. Yes	-0.29	0.75 (0.65, 0.86)	<.0001
Site	-0.74	0.48 (0.42, 0.54)	<0.001
Race and Study Group			
Black-Retrospective*	-0.24	0.79 (0.65, 0.96)	0.02
Black-Intervention*	0.48	1.6 (0.90, 2.9)	0.11
Black-Concurrent†	-0.37	0.69 (0.49, 0.96)	0.03
White-Intervention*	0.50	01.6 (1.03, 2.7)	0.04
Black-Intervention†	0.08	1.1 (0.59, 2.0)	0.80
Black-Intervention**	-0.02	0.98 (0.46, 2.1)	0.95

\*White retrospective cohort is the referent group.

†White concurrent cohort is the referent group.

\*\*White intervention cohort is the referent group

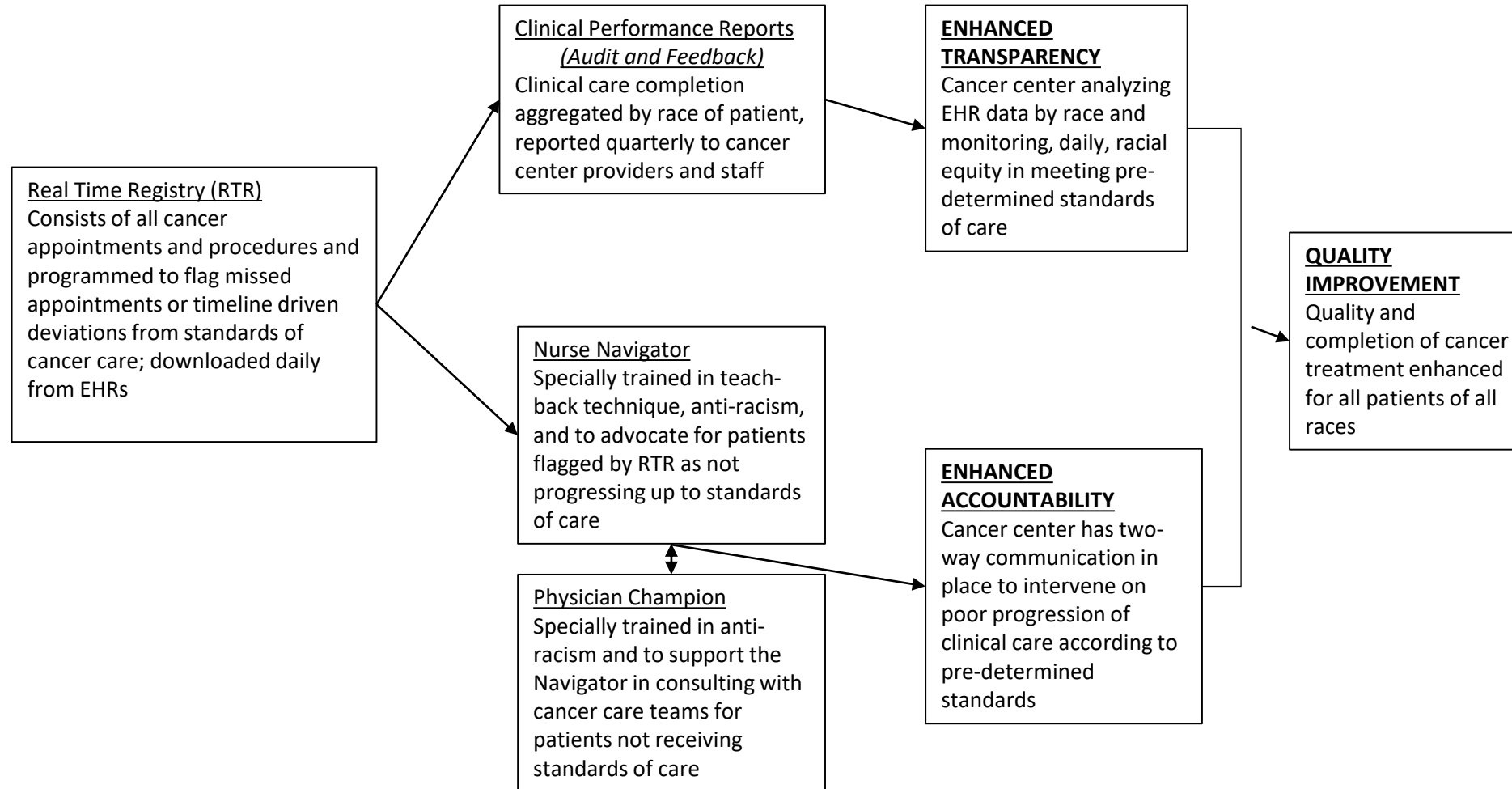


Figure 1. Patient Enrollment, Randomization, and Progression in ACCURE.

